

Cognitive Scale for Down syndrome (CS-DS)

This questionnaire should be completed by someone who knows the individual well (e.g. parent, care giver).

Read each statement carefully and think about the individual's behaviour over the last two months. Decide whether the statement was never/rarely true, sometimes true or often/always true. Put a cross in the correct column. Please answer every item as best you can, and do not skip any items.

When completing the questionnaire please consider the following guidelines:

- When thinking about tasks or activities, consider things the person is physically able to do
- Where appropriate, examples of simple tasks may include setting the table, tidying, making a simple meal or hot drink, homework
- For questions that ask about communicating, think about the individual's usual method of communicating (e.g. speaking, Makaton), as well as any gestures and/or behaviours

Participant ID:

Date:

Informant relationship to participant:

Length of time informant known participant:

Frequency of contact between informant and participant:

Does the individual speak (circle the correct response)

Not at all A little A lot

List the languages the individual uses (including Makaton)

Does the individual have problems with vision (circle the correct response) – if yes give details

Yes No Details:

Does the individual have problems with hearing (circle the correct response) – if yes give details

Yes No Details:

	Never/ rarely true	Sometimes true	Often/ always true
1. Needs to do something as soon as they're asked to otherwise they will forget to do it			
2. Finds concentrating on tasks difficult			
3. Understands questions involving a decision (do you want to do this or that)			
4. Tends to use the same words or gestures to describe things (i.e. uses a limited vocabulary)			
5. Remembers where they put something recently (up to half an hour ago)			
6. Strays from the topic when communicating			
7. Ignores irrelevant distractions in the environment			
8. Can explain reasoning behind decisions (e.g. why they have chosen one activity over another)			
9. Takes a long time to start a task			
10. Can't communicate simple details about what they're doing			
11. Is stubborn			
12. Wouldn't remember the basic plot of a TV show/film they've seen earlier that day			
13. Wouldn't recall an important event from at least 6 months ago (e.g. a trip they've been on)			
14. Goes into a room and forgets what for or why			
15. Makes an effort to organise items (e.g. socks in one drawer, stores cutlery correctly)			
16. Understands instructions involving a series of steps			
17. Takes care when completing task			

	Never/ rarely true	Sometimes true	Often/ always true
18. Finds it easy to switch from one task/activity to another			
19. Knows basic information about other people (e.g. name, relation to self)			
20. Easily completes tasks that involve more than one step			
21. Loses belongings			
22. Finds things to do to occupy time by themselves			
23. Gets distracted easily			
24. Often repeats themselves or asks the same question without noticing			
25. Doesn't rush through tasks			
26. Doesn't respond when talked to			
27. Finishes tasks they start			
28. Remembers what they did today			
29. Misjudges how long something will take			
30. Fidgets (e.g. taps fingers or bounces legs)			
31. Has a short attention span			
32. Remembers if there is something outside of their usual routine planned for the day (e.g. going to the doctors)			
33. Carries out simple everyday tasks without prompting (e.g. going to the toilet, having a meal)			
34. Finds it hard to get over minor problems easily / fixates on minor problems			
35. Needs to be prompted to get dressed and ready for the day			

	Never/ rarely true	Sometimes true	Often/ always true
36. Loses track of what they are doing in the middle of a task			
37. Overreacts to situations or problems (e.g. gets excessively angry or sad)			
38. Doesn't notice when they make mistakes			
39. Is patient when waiting their turn			
40. Doesn't plan ahead for tasks (e.g. doesn't leave enough time or have the correct materials)			
41. Forgets when their birthday is			
42. Doesn't change their mind once they've made a decision			
43. Tell somebody if they needed help with something (e.g. if they can't find something they're looking for)			
44. Remembers everything they need to do in the morning			
45. Behaves inappropriately (e.g. makes inappropriate comments, actions or noises)			
46. Wouldn't remember someone they met earlier that day			
47. Doesn't understand sayings that are not meant literally (e.g. chip on the shoulder)			
48. Impulsively acts or speaks without thinking			
49. Can communicate the details of an experience (e.g. who was there, what they did)			
50. Keeps belongings in set place			
51. Finds it difficult to keep themselves busy			
52. Easily remembers simple instructions			

	Never/ rarely true	Sometimes true	Often/ always true
53. Isn't bothered when their daily routine is changed without warning			
54. Wouldn't be able to give simple instructions (e.g. the rules of a game)			
55. Completes simple tasks without making mistakes			
56. Could decide on their own what to do later that day (e.g. watch a film, paint etc.)			
57. Easily concentrates on TV shows/activities			
58. Is disorganised (e.g. keeps room/bathroom in a mess)			
59. Finds it easy to sit still			
60. Starts tasks they need to do without being repeatedly prompted			
61. Finds it easy to multi-task (doing more than one thing at a time)			

Has the person shown any changes in abilities over the last year?

Cognitive Scale for Down syndrome (CS-DS) scoring

The following questions are scored 0 for never/rarely true, 1 for sometimes true, 2 for often/always true:

3, 5, 7, 8, 15, 16, 17, 18, 19, 20, 22, 25, 27, 28, 32, 33, 39, 43, 44, 49, 50, 52, 53, 55, 56, 57, 59, 60, 61

The following questions are scored 2 for never/rarely true, 1 for sometimes true, 0 for often/always true:

1, 2, 4, 6, 9, 10, 11, 12, 13, 14, 21, 23, 24, 26, 29, 30, 31, 34, 35, 36, 37, 38, 40, 41, 42, 45, 46, 47, 48, 51, 54, 58

The following questions were chosen as a part of the executive function domain:

2, 7, 9, 11, 15, 17, 18, 21, 22, 23, 25, 27, 29, 30, 31, 33, 34, 35, 37, 38, 39, 40, 42, 43, 45, 48, 50, 51, 53, 55, 56, 57, 58, 59, 60, 61

The following questions were chosen as a part of the memory domain:

1, 5, 6, 12, 13, 14, 19, 20, 24, 28, 32, 36, 41, 44, 46, 52

The following questions were chosen as a part of the language domain:

3, 4, 8, 10, 16, 26, 47, 49, 54